Our Nation’s Long-Term Care Crisis and Medicaid: The Need for a Systemic Solution
Introduction

The leading health care challenge of the early 21st century is long-term care and its financing. For all of those living above the poverty line, the inability to gain access to affordable, competent long-term care is the most significant threat to the physical, emotional and financial well-being of the afflicted individual and his or her family.

Seniors have limited options in regard to paying for long-term care. A comprehensive, standardized system to deliver quality long-term supports and services is lacking and clearly needed. The failure to develop a more systemic solution to this growing crisis continues to strain federal and state budgets and puts added stress on families and caregivers unable to cope with the financial and emotional costs.

Two fundamental issues contribute to this dilemma. First, government programs created in the mid-1960s intended to alleviate the risk of impoverishment for persons needing essential health care services are outdated and constrained from reaching discrete segments of today’s population in need of long-term care services. For example, Medicare, a program designed in 1965 for a population with very different demographics than today, as well as most health insurance programs, do not cover custodial or long-term care services. This puts most Americans with diseases such as Alzheimer’s, Parkinson’s, ALS (Lou Gehrig’s disease), or Multiple Sclerosis in serious financial jeopardy as they struggle to pay for care. Ironically, it is only once they have become impoverished, having depleted their savings and assets, that the federal-state Medicaid program is able to offer assistance. With nowhere else to turn, Medicaid becomes their program of last resort.

Second, people are living longer. The World Health Organization reports that between 1990 and 2012, the average life expectancy at birth in the U.S. increased from 75 to 79 years. More striking is that in 1965, the year Medicaid and Medicare was enacted, the average life expectancy at birth was 70.2 years. With these added years of life has also come the need to provide for extended medical care — for chronic as well as acute diseases and maladies. Add to the mix the Baby Boomer generation, defined as persons born between 1946 and 1964. This cohort numbers 76.4 million in 2012 and accounts for about one-quarter of the U.S. population. As these individuals age and require care, the cracks in the long-term care system will continue to widen.

3 The number of people needing LTSS is expected to grow in the next few decades as the Baby Boom generation ages, although trends in age-adjusted rates of disability now appear to be holding steady after a period of improvement for older populations. “The number of individuals with Alzheimer’s and other dementias will increase as the number of elderly people increases. By 2050, the annual number of new cases of Alzheimer’s is projected to more than double.” Commission on Long-Term Care, Report to Congress, at pg. 11, http://ltccommission.lmp01.lucidus.net/wp-content/uploads/2013/12/Commission-on-Long-Term-Care-Final-Report-9-26-13.pdf (Sept. 2013) (citing Alzheimer’s Association, “Alzheimer’s disease facts and figures”).
Historically, the lion’s share of the responsibility for providing long-term care has been taken on by unpaid caregivers. Each year, adult family members and friends, primarily women, provide over 80% of caregiving support.¹ Researchers estimate the value of this unpaid caregiving at well over $450 billion per year.² By contrast, paid caregiving costs the public and private sectors about $219.9 billion, about a quarter of which is paid out-of-pocket by individuals and their families.³ Nursing home care costs alone were $81,030 for a semi-private room and $90,520 for a private room per year on average, with 36% of that paid out-of-pocket by individuals and their families.⁴ The cost in terms of time and resources is extraordinary and ever escalating.

This is the reality: there is an obvious hole in our health care safety net, and, absent decisive action, there will be no relief, even for families with resources.

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The Practice of Elder Law and its Relationship to Long-Term Care Planning

Trying to guide people in need through the long-term care maze is a constant challenge for Elder Law attorneys. Elder Law is a specialized area of law that involves representing, counseling, and assisting the elderly and individuals with disabilities and their families in connection with a variety of legal issues. It is a holistic approach to the practice of law that focuses on the individual rather than a particular area of law. There are more than 20 distinct areas of concern that fall under the umbrella of Elder Law in which Elder Law attorneys provide support to older and disabled people, including but not limited to estate planning, wills, advance directives, trusts, guardianships, government benefits, and long-term care planning.

Many Elder Law attorneys are members of the National Academy of Elder Law Attorneys, a national, non-profit association composed of more than 4,500 attorneys. NAELA provides information, education, aspirational practice standards, networking, and assistance to lawyers, bar organizations, and others who deal with the many issues involved with providing legal services for the elderly and people with special needs.

NAELA sets the highest ethical expectations for its members in all areas of legal counseling and believes that access to Elder Law counsel is critical, especially to the welfare of lower and middle-income seniors across the nation.

Those Who Seek Long-Term Care Guidance—Real People with Real Needs

Long-term care (LTC) clients are most often older adults in their sixties and beyond who are in need of or are concerned about long-term care services. Although on occasion they are seeking advice on planning ahead, it is far more often the case that the need for care is upon them and they want to understand how to access quality care and be able to afford it without becoming impoverished.

This concern is understandable. According to researchers, “roughly 70 percent of those who turn age sixty-five will have long-term care needs at some point in their lives.”

The great majority of these Americans are middle-income seniors who turn to Medicaid with the hope that it will cover most of their long-term care needs, including nursing home care. Many are children of the Great Depression and are World War II veterans who have lived “the American dream,” providing for their families and paying taxes, never before seeking a “government handout.” Most of them are women, who, after losing their husbands to the devastation of chronic illness, have to suffer the indignity of impoverishment and financial dependence on family or the government. Clients are also younger persons with disabilities and caregivers, predominantly family members, who are caring for or concerned about a loved one.

When Elder Law attorneys implement long-term care planning, it is part of a larger planning process that examines the full range of long-term care options, issues, and costs relevant to the client’s circumstances. By considering all available options and implementing those that make the most sense based on the individual’s specific circumstances, effective planning:

1. Helps to ensure better quality of care, which is what most families want. By planning, families are able to keep loved ones in community-care settings longer, and resources are preserved to cover essential needs, such as those that Medicaid does not cover when the individual enters a nursing home. 9
2. Helps to protect spouses or dependents who remain in the community from financial impoverishment, focusing on both current and future needs.
3. Supports family caregiving, which accounts for 70-80% of the long-term care in this country.
4. Supports setting aside funds to supplement the basic services Medicaid provides.

Programs Available to those in Need of Long-Term Care

When organizing long-term care, individuals and families must navigate the benefits and requirements of numerous programs, support systems and products. A brief overview follows.


9 According to the AARP Public Policy Institute, 89% of people 50 and older want to remain in their homes as long as they can. Providing More Long-term Support and Services at Home: Why It’s Critical for Health Reform, http://assets.aarp.org/rgcenter/health/fs_hcbs_hcr.pdf (2009). And while home and community-based services (HCBS) does increase short-term costs, studies have shown that expansion of these programs leads to a reduction in institutional spending and delivers long-term cost savings. H. Stephen Kaye, Mitchell P. LaPlante, and Charlene Harrington, Do Noninstitutional Long-Term Care Services Reduce Medicaid Spending?, 28(1) Health Affairs at 262, http://content.healthaffairs.org/content/28/1/262.full.pdf+html (Jan./Feb. 2009).
The Role of Medicare

Medicare is an unfulfilled promise for many Americans with chronic illnesses. Under this program, eligibility is determined by the type of illness one has. In general, if one has an acute illness like heart disease or cancer, Medicare provides comprehensive care. Medicare provides very limited coverage in a nursing home setting (up to 100 days), and it does not cover long-term care at home unless the senior needs skilled care and then the services covered are highly restricted in scope and duration. Private health insurance programs generally do not cover services beyond short-term rehabilitation care.

The Role of Medicaid

Medicaid provides coverage for chronic illnesses. However, unlike Medicare, Medicaid is a program with income and asset limitations requiring virtual impoverishment to qualify for benefits, which generally provide for basic care services. Eligibility is complex and, because it is a joint federal-state program, varies from state-to-state. When people do become eligible for Medicaid, regardless of whether they have engaged in long-term care planning, they are required to pay all but a small portion of their income each month for their care. Medicaid then pays whatever the difference is between that amount and the Medicaid rate. Thus, costs to Medicaid are always mitigated by the Medicaid recipient’s monthly income.

The Role of Long-Term Services and Support

The role of the aging network and the services and supports funded by the Older Americans Act and state governments can be critical in helping to keep older adults with multiple chronic illnesses in their homes longer. For individuals with means, these programs are out of reach since they are designed to target those with the greatest economic and social needs.

Elder Law Attorney Helps Family Navigate Complicated and Confusing Medicaid Regulations

When Huntington’s disease struck several members of her Michigan family, Angela Denavarre talked with doctors and local health officials looking for guidance on how to finance the expensive treatment for her children. She was often referred to complicated and confusing regulations that govern Medicare and Medicaid eligibility.

“One day I saw a story in the local newspaper that was an interview with attorney Patti Dudek,” Ms. Denavarre said recently. “I called and she helped me get a children’s’ Medicaid waiver and establish a special needs trust for my 10-year-old son, Anthony.”

“Anthony was able to get services at my home and lived independently until he passed away.”

Anthony’s father Ed also contracted Huntington’s and the special needs trust provided end-of-life care for him and for two more children -- Katie and Edward Jr. who had also contracted the disease.

“Without Patti, I never would have gotten through this.”

Ms. Denavarre credits Elder Law attorney Patricia E. Kefalas Dudek of Farmington Hills, Mich., as the one person who provided clear and effective counsel during what was a troubled time for her and her family.

“Without Patti Dudek, I never would have gotten through this,” she said.

Ms. Dudek praised the courage of Ms. Denavarre and her family.

“Through the use of legal and ethical Medicaid planning, we were able to improve the quality of care for several members of her family,” Ms. Dudek said. “We were able to avoid institutionalization and save our state thousands and thousands of dollars.”


Supra n. 3, Commission on Long-Term Care at 27.
The Role of Private Long-Term Care Insurance

Long-term care insurance (LTCI) products provide one planning option for some seniors, and Elder Law attorneys discuss this option with clients as part of a comprehensive evaluation of long-term care options. However, the long-term care insurance sector offers products that address only a small portion of long-term care needs, typically paying for less than 12 percent of all long-term care expenses. At present, the potential to meet financing needs has been limited by the proportion of the population with sufficient lifetime earnings and asset accumulation to afford such insurance. LTCI, like life insurance, is most affordable when purchased well before retirement age is reached or the need is immediate. Thus, LTCI products are beyond the reach of most retirees. In addition, unlike Medicare and Medicaid, individuals applying for LTCI usually must undergo a health underwriting screen.

The Role of Private Pay

This is what many seniors and their families do: privately pay. By privately paying, they can better control the quality of care and the choices available in selecting the type of care. The problem here is simple and widespread: Most seniors do not have financial means to pay for necessary care and daily living expenses for an extended period of time.

Recent Eligibility Changes have Limited Access to Care to Vulnerable Populations

The Deficit Reduction Act of 2005 was the last significant change to the Medicaid eligibility rules. It made it more difficult for seniors who need long-term care to access Medicaid. Yet, while further constricting access to Medicaid, no alternative avenues to accessing long-term care have been advanced. Moreover, purchases of long-term care insurance, which the heightened eligibility rules were intended to encourage, have not increased, with many insurers exiting the market.

While appropriately deterring efforts to artificially qualify for coverage, these changes have had the ancillary effect of creating barriers for those with legitimate circumstances to accessing critical care and services under Medicaid. These changes include:

**The five-year look back rule.** This rule has placed an unfair burden on seniors who are not able to provide supporting documentation of their financial transactions for the five years prior to seeking Medicaid nursing home care. For single individuals, there is often a spend down to qualification. Many seniors have difficulty providing supporting documentation, especially those who have not shared their personal finances with anyone or with no close family members. Even when they have, few are versed in the bookkeeping requirements. And, the problem is exacerbated if the senior has a chronic disease that impacts adversely on memory.

**Change in the transfer penalty rules.** For nursing home care, the transfer does not start until the Medicaid applicant is residing in a nursing home, files for Medicaid, and is otherwise eligible for Medicaid but for the transfers. This has effectively prevented seniors from accessing Medicaid who transferred assets within the five-year look back period, even if they have spent down by paying privately for care until their resources were depleted.

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12 A 2003 in-depth analysis of long-term care insurance (LTCI) concluded that the private LTCI market has emerged mainly in response to the demands of a small, relatively affluent market, and that policies are not affordable for most people. Mark Merlis, *Private Long-Term Care Insurance: Who Should Buy It and What Should They Buy?*, Prepared for the Henry J. Kaiser Family Foundation, http://kaiserfamilyfoundation.files.wordpress.com/2013/01/private-long-term-care-insurance-who-should-buy-it-and-what-should-they-buy-report.pdf (Mar. 2003). While some have argued that Medicaid “crowds out” the availability of long-term care insurance, the relationship between Medicaid and LTCI is much more nuanced. The Commission on Long-Term Care notes that analysts disagree on the significance of the “crowd-out” effect. “Features of the products, the insurance market and some regulatory requirements limit the value and pricing of LTCI, including underwriting standards that prevent many individuals from qualifying, high monthly premiums, policy forfeiture rules, limits on benefits, and a lack of public understanding and confidence in private LTCI products.” *Supra* n. 3, Commission on Long-Term Care at 27-28.

13 *Supra* n. 3, Commission on Long-Term Care at 28-29.


15 Seniors often make transfers that have nothing to do with qualifying for Medicaid, such as giving a gift, helping a child purchase a home, or providing them support when they are unemployed. Moreover, these gifts are often made without the knowledge of the need for long-term care in the future, as anticipating future health and long-term care needs is often an impossibility.
Restrictions on the use of annuities. Annuities can generate needed income. But, many seniors are sold annuities as investments, only to discover later that they adversely affect Medicaid eligibility, because they do not meet the appropriate rules. The law now protects the state by treating the purchase of an annuity as a disqualifying transfer of assets unless the state is named as remainder beneficiary after the community spouse or a minor or disabled child up to the amount of Medicaid paid for the institutionalized individual. An annuity purchased by an annuitant applying for Medicaid for nursing home or other long-term care services also must be irrevocable and non-assignable, actuarially sound, and provide for payment in equal amounts with no deferral and no balloon payments.

These changes have left many frail and vulnerable seniors unable to access necessary care. Without a viable solution, vulnerable citizens will continue to face impoverishment to finance their long-term care needs, often breaking apart families in the process. Elder Law attorneys provide counsel in this context, helping their clients through the current maze of complex, conflicting, and often callous policies.

Select Paradigms for Addressing Long-Term Care

Numerous paradigms for addressing the long-term care financing challenge have been discussed. Each has its virtues and costs. These include:

• Federalizing Medicaid to provide uniformity in standards of care and other Medicaid rules.
• Adding long-term care to Medicare, the federal health insurance program that covers Americans aged 65 and older (and other specified groups).
• Adopting a “social insurance” model for providing LTC, which would operate by simultaneously mandating that everyone buy health insurance, and that long-term care be included in that insurance thereby spreading the cost over the greatest possible base.
• Establishing a basic public benefit (cash or service) available to people assessed as meeting a specified threshold of functional impairment after a waiting period based on income at or near retirement age — shorter for people with lower incomes and becoming longer at higher incomes (modified for people under age 65).16
• Adjusting the Medicaid long-term care eligibility rules to consider income only, as opposed to considering both income and assets. Imputing income from assets would increase the number of people who get benefits. In turn, these beneficiaries could contribute income derived from their assets toward the cost of care, thereby lessening the burden of care for these individuals on the government.
• Modeling a program after the New York State Compact for Long-Term Care (Compact), a public/private risk-sharing program that redefines the relationship between New York state residents and their government concerning the financing of long-term care. The Compact removes Medicaid as the main player and residents of and the State of New York pledge mutual responsibility. An individual can apply for the Compact when they are deemed to be chronically ill.17

Moving Forward

NAELA believes that long-term care delivery, accessibility and financing is a growing national problem that requires a national solution. If we fail to address this hole in our nation’s health care safety net, the broader societal costs will far outstrip those associated with Federal and state Medicaid outlays.

Politics cannot be the driving factor in this needed dialogue; the focus must be on the American people in need, our two most vulnerable populations, older Americans and people with disabilities, with the goal that these individuals:

• Receive the best quality health care without being impoverished by the high cost of such care;
• Receive that high quality care in their homes if possible; and,
• If they are not able to stay in their homes, find affordable alternative housing and care arrangements, such as assisted living or nursing care.

As policy makers endeavor to fashion an approach to making long-term care accessible and affordable, NAELA offers an informed perspective based on the thinking of leading researchers in the Elder Law arena and the “boots-on-the-ground” experience of practicing Elder Law Attorneys who see clients in long-term care crisis on a daily basis.

